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ABSTRACT

A consumer viewpoint on the use of technology by disabled persons is presented. Reasons for not solving the problem of technological underutilization are proposed. Goals for evaluating the appropriateness of a technology should not be rigidly defined; persons who do this actually set limitations in the guise of being "realistic." At present there is no one source of information about all technical aids; a better procedure is to seek clinical engineering services to meet individual client needs. Another recommendation centers on the establishment of technical assistance for projects concerning the disabled and the use of data from follow-up procedures. Consumer reports on technical aids and technical equipment demonstration units are also advocated. Comments on pricing and on the government's role in research and development conclude the presentation. (CL)

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UTILIZATION OF TECHNOLOGY; CONSUMER PERSPECTIVE

MARGARET C. PFROMMER

ABSTRACT

Technology has impacted the lives of persons with disabilities in a positive way. However, only a small number of persons are benefiting from these technical products and services. The problem of technological underutilization has not been resolved, in my opinion, for three reasons.

First, when obstacles to the application, documentation, reimbursement, and manufacture/distribution are identified, they are treated as inviolable. Second, seldom, if ever, is a direct line of accountability set between those who have responsibility and the recipients, or supposed recipients, of the benefits of technical products and services. Third, appropriate consumers are excluded from attempts to resolve issues and solve problems.

The perspective I am bringing to my subject is that of an experienced and informed consumer. I am a typical consumer as I rely on technical products and services to maintain and increase my independence and productivity. In addition, I have for many years had the opportunity to work with professionals in the research, development, and application of technologies. Although this affiliation requires that I function with a high level of professionalism, it is understood that my primary accountability is to persons with disabilities. From this unique position I have been able to perpetuate the consumer perspective.

A need exists for an increased number of well-trained persons to work in all service delivery areas of the technical aids for persons with disabilities identity. Equally important is the need to upgrade the skills of professionals presently responsible for applying technology.

In order to meet the shortage of qualified professionals, two universities, Virginia and Drexel, are currently providing training for clinical engineers. The University of Virginia is accepting both engineers and therapists in its program. The engineer develops clinical skills, and the therapist learns engineering concepts. Only time will tell if this training is adequate and if graduates will get into actual, competent application of technical aids in sufficient numbers.

My own experiences with inadequate professional application of technology led me, several years ago, to conclusions now supported by the 1982 Office of Technology Assessment

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Report which states "Those providers who are permitted by the structure of delivery and reimbursement systems to prescribe technologies for disabled people may not always be the most appropriate ones to do so." The above quotation shows that not only consumers question professional competencies, but that professional peers also are concerned. Those inappropriate providers are usually the parties whose values and goals determine the appropriate application of technology.

I have had the good fortune to work with professionals who are skillful in their application of technology. I also have had the misfortune of being the client of other professionals whose incompetence contributed to many years of unnecessary discomfort, dependence, and isolation.

Biases on the part of professionals often interfere with good service delivery.

As a consumer, I object to the whole idea of rigidly defined goals for evaluating the appropriateness of a technology. Many persons who define goals actually set limitations under the guise of "being realistic." For example, some professionals have refused to prescribe a pneumatic wheelchair control (puff-and-sip) for persons on ventilators because the professionals lack the knowledge that such persons can make good use of this control device.

It is not possible to explicitly state goals. What is possible, and often happens, is that a prescribed technology opens opportunities undreamed of by any of the prescribers; a desire and need for additional technology is created. In my work applying technology, I have often been amazed with the positive synergistic effect of good application and use of aids. Professionals who straightjacket themselves by explicitly defining goals deprive themselves, their clients, and the world of the ultimate benefits of technology. I am convinced that the misuse and misapplication of technology causes and perpetuates disabilities.

As an informed consumer, I understand and sympathize with some of the problems of good service delivery. Common complaints from people delivering engineering services are: (1) they have to put much time and effort into the search for information about the proper application of technical aids and their benefits, and (2) in many cases, in order to receive payment for their services, they must search for reimbursement. The investment of time and energy in these two areas reduces the time and effort that can be expended in their rightful area of expertise.

The proper application of technical aids is a very time consuming task. Collection, documentation and better information sharing could reduce the hours and efforts.

Unfortunate information gaps exist. I am occasionally contacted by rehabilitation practitioners, vocational counselors, and others, requesting a source of information for technical aids in general. It is apparent that these people do not have the time or knowledge to contact many different sources and want to plug into one source; they would like to press a button and have the answer fall into their laps. I question the concept that a central data bank is the total solution. The information in such a bank would probably be limited and the data bank concept presently leaves out the knowledgeable advocate, person who is not a manufacturer/distributor who can explain subtle differences in devices and properly apply a particular device to a specific need.

My answer to callers for general information is there is presently no one source where

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a person can obtain all information about all technical aids. It seems to me that, at this time, a better procedure is to seek clinical engineering services to meet individual client needs. In the process, the practitioner will gain experience and awareness of other sources of information.

Probably the most valuable resource for professionals applying technology is attendance at workshops and conferences where conference proceedings may be obtained and where valuable contacts with other professionals in the field may result in future interaction.

Professionals in the research and development area also lack a data bank from which to draw over-all and unified information. Most of the information is scattered, know only through the personal experience of researchers. Although the journals are useful, the most valuable way to gain information seems to be through personal contacts.

As to those who apply technology, researchers and developers must spend disproportionate amounts of their time in searching for current information in order to do the best job possible and to avoid duplication of effort.

There still are other groups who need good information in order to better use technology: policy makers, manufacturers, marketers, and distributors of technological products. Four specific resources that would be helpful to all these groups are (1) the greater use of clinical engineers, (2) technical assistance for the disabled projects, (3) a consumers report on technical aids, (4) and equipment demonstration units.

Although individuals in the rehabilitation professions have recognized the usefulness of clinical engineering for persons with disabilities, the discipline has seemingly not been accepted as an integral part of the rehabilitation process. Few facilities have clinical engineers on their staffs and only a small number of vocational counselors use the services of engineering clinics for their sêverely disabled clients.

Greater use of clinical engineers would insure that better selections of appropriate devices for individual disabilities are made.

(1) The clinical engineer works with disabled persons to become aware of their individual needs and then applies unique technical aids to meet those needs.
(2) The engineer guides disabled persons through the maze of available aids by experience and information.
(3) The engineer makes suggestions for modifications (e.g., method of control) that may determine whether a disabled person uses or does not use precribed devices to their fullest potential.

Other than a few talented rehabilitation professionals, there are no professionals that can provide this service other than clinical engineers.

Another service that would be beneficial is the establishment of technical assistance for disabled projects. Projects would allow disabled persons to obtain maximum benefit from their technical aids. One aspect of such a project could be the organization of volunteers for use in hands-on activities and the modification of home areas and/or job sites. Modifications could include building or altering work tables, installing simple electronic equipment such as environmental systems, changing doorknobs., providing interior and exterior ramps. The proposed service component could also collect information about technical aids and materials for use in modification. In some

cases, ideas and designs might be provided for the user. Further help could be provided by estimating costs, by suggesting sources for funding, and by supplying standard specifications for modifications to doorways, ramps, and other environmental blocks.

The greatest value to all concerned probably lies in the data obtained from follow-up procedures. Data may be used:

(1) to see if a particular modification works well and could be applied to another persons needs.
(2) to gain new ideas.
(3) to supply information to manufacturers of technical aids that may be helpful in design modifications.
(4) To provide information to third-party payers so that they can include the cost of environmental modifications with the technical aid.
(5) to provide a realistic picture of the current cost of environmental modifications.

A consumer report on technical aids would be of great value to third-party payers, prescribers, and users. This would report evaluations independent of the manufacturers. The evaluation of equipment could have three aspects:

(1) testing of engineering performance (the technical specifications).
(2) studying a device's applicability, reliability, serviceability, and maintenance system.
(3) examining the subjective responses of the user and of professionals involved with its application.

Technical equipment demonstration units would be of particular interest to prescribers and third-party payers. These units could provide additional assurance that the most appropriate technical aid is selected and the best possible use made of available funds. What should be of equal importance to agency professionals is that a wise choice of technical aids including a careful expenditure of money, has the ultimate result of providing a better quality of life for their clients with disabilities. A technical equipment demonstration unit ought to meet certain requirements:

(1) It should offer technical assistance from knowledgeable persons who can direct a potential user to appropriate technical aids and guide him through a process of hands-on use.
(2) It should provide oral and written information on technical aids including their similarities and differences, to assist in a final selection.
(3) It should display a wide variety of technical aids available for hands-on use set in simulated typical environments.
(4) It should be cooperatively planned by all rehabilitation facilities in the area so that all would feel comfortable using the service as part of their rehabilitation programs.
(5) Because of the large investment in set-up and maintenance, it should be located in a densely populated area and serve as many people as possible.

The opportunity for consumers to try a technical aid before they, or their funding agency, makes an investment is especially important in view of the present practice of requiring full payment before a device is ordered.

Even when well-qualified,

well-informed professionals have prescribed technology for informed consumers who have made good choices among the available aids, too often there remain financial barriers to the acquistion of these aids.

The systems of reimbursement that do not pay for the more expensive technologies do not provide options for consumers to use their own resources to make partial payment. Professionals continue to allow themselves to be compromised by the payment system; rather than prescribe the appropriate device, they settle for one that is affordable. The outcome is a consumer that receives only partial benefits or one that is further handicapped. Reimbursement systems should be expanded to provide more sophisticated technologies that clearly can, be justified on the basis of cost effectiveness and/or improved quality of life. Most modern technology is really non-medical and should not require the added expense of a physician's prescription.

There is a reluctance on the part of some (distributors, for example) to change the status of technologies clearly not medically oriented (e.g. wheelchair batteries) to "non-medical" because of the reimbursement system. For the consumers, this perpetuates their image as sick people who depend on the medical system for their very existence.

Much technology for persons with disabilities has been generated by government-funded research and development programs. These programs have been criticized for putting a low priority on production, marketing, and diffusion activities. It would be more accurate to say that, because of their limited resources, research and development organizations have been forced to place a low priority on those activities. Because research and development organizations are not mandated to engage in the production, marketing, and diffusion of technologies, any efforts in this area are not recognized when grants are being awarded. Actually, the typical organization, having put forth great effort in developing a product or service, is eager to see it provide benefits to as many people as possible. It is the manufacturer who could be criticized for not putting forth efforts to conduct activities such as demographic studies which could lead to the development of good marketing strategies for the wide-spread use of technical products and services.

There is a need for better relationships between manufacturers and customers. Many companies are too distant from the people who use their products, thus, they fail to operate with a fine sensitivity to concerns of their customers.

The manufacturer/distributor should assume responsibility for a reliable product that can be adequately maintained. If the product is good and meets a need, the user will become inevitably dependent upon it. Even the most reliable equipment breaks down; a valuable service could be provided by loaning or renting a spare. This could prevent a complete change of life style and avoid a shift in dependency back to human beings.

One observation I have made through the years has to do with the pricing of certain technical aids. Some companies bear the cost of their own research and development. Others benefit from research and development programs funded by the government. Yet, those companies that benefit from government research sell devices very similar to those offered by others at approximately the same cost, with no savings passed on to the consumer.

I have heard the government repeatedly condemned for insensitivity

to issues regarding persons with disabilities and in many areas the criticism is valid. However, in the area of research, development, and use of technology, government funded programs, even with limited resources, have played a leadership role.

As the private sector continues to lag behind, I look to the government to stimulate that sector's interest and to make its own participation more meaningful. For example, congress might legislatively charter a private organization to provide marketing and production-related services, or to conduct evaluation projects that are clearly and cleanly separated from the functions of assisting the marketing of products. I very strongly urge that a component of any evaluation process include a consumers report.

The government has another great need to coordinate the activities of its separate agencies and departments to bring good products and services to persons with disabilities. This opinion is not mine alone, but is an opinion I have heard expressed by consumers and professionals alike.

I would like to see a greater number of qualified consumers working to solve this problem and other problems on a national level. Consumers working at the national level need to be truly representative of the population they serve. Qualified consumers are persons who (1) have a disability, (2) possess social maturity, (3) use technical products and services, (4) participate in consumer organizations or demonstrate good contact with the community of persons with disabilities, (5) represent the point of view of a sizeable number of persons with varying disabilities (being aware of a variety of lifestyles and experiences), and (6) possess a working knowledge of the area in which they are participating.

There is a consensus of all persons involved with technology and handicapped people that independence and employability are not only important human aims, but also sound economic goals. It is generally recognized that the good use of technical products and services will permit persons with disabilities to earn their own living and/or reduce assistance.

No matter how well people are equipped with technical devices and with personal and intellectual capabilities, the disincentives of our society prevent them from reaching their full potential for independence and employability. Disincentives include inaccessibility to buildings, programs, and facilities, archaic social security and tax structures, and attitudes which impede role changes.

Encountering and resolving the many problems connected with underutilization of technical products and services can be overwhelming if we permit them to be, but, along with you, I am ready to commit myself to the task.